



HHS Public Access

Author manuscript

Curr Opin Nephrol Hypertens. Author manuscript; available in PMC 2024 January 01.

Published in final edited form as:

Curr Opin Nephrol Hypertens. 2023 January 01; 32(1): 81–88. doi:10.1097/MNH.0000000000000848.

Changing Landscape of Living Kidney Donation and The Role of Telemedicine

Fawaz Al Ammary, MD PhD⁽¹⁾, Abimereki D. Muzaale, MD MPH⁽²⁾, Ekamol Tantisattamo, MD MPH⁽³⁾, Ramy M. Hanna, MD⁽³⁾, Uttam G. Reddy, MD⁽³⁾, Suphamai Bunnapradist, MD MS⁽⁴⁾, Kamyar Kalantar-Zadeh, MD PhD⁽³⁾

⁽¹⁾Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland

⁽²⁾Department of Surgery, Johns Hopkins University School of Medicine, Baltimore, Maryland

⁽³⁾Department of Medicine, University of California Irvine, Orange, California

⁽⁴⁾Department of Medicine, University of California Los Angeles, Los Angeles, California

Abstract

Purpose of review: There has been a decline in living kidney donation over the last two decades. Donors from low-income families or racial/ethnic minorities face greater disproportionate geographic, financial, and logistical barriers to completing lengthy and complex evaluations. This has contributed to the decreased proportion of these subgroups. The authors view telemedicine as a potential solution to this problem.

Recent findings: Since the initial decline of donors in 2005, biologically related donors have experienced a lack of growth across race/ethnicity. Conversely, unrelated donors have emerged as the majority of donors in recent years across race/ethnicity, except for unrelated black donors. Disparities in access to living kidney donation persist. Telemedicine using live-video visits can overcome barriers to access transplant centers and facilitate care coordination. In a U.S. survey, nephrologists, surgeons, coordinators, social workers, and psychologists/psychologists across transplant centers are favorably disposed to use telemedicine for donor evaluation/follow-up beyond the COVID-19 pandemic. However, with the waning of relaxed telemedicine regulations under the Public Health Emergency, providers perceive payor policy and out-of-state licensing as major factors hindering telemedicine growth prospects.

Summary: Permanent federal and state policies that support telemedicine services for living kidney donation can enhance access to transplant centers and help overcome barriers to donor evaluation.

Keywords

Telehealth; Access to Health Care; Kidney Transplantation; Living Donor; COVID-19 Pandemic

Contact Information: Fawaz Al Ammary, MD PhD, The Comprehensive Transplant Center, Division of Nephrology, Johns Hopkins University School of Medicine, 600 N. Wolfe Street, Carnegie building, Suite 344-C, Baltimore, MD 21287, +1 443-287-9631 (Office) +1 410-367-2259 (Fax), fawazalammary@jhmi.edu.

Conflicts of interest
None.

INTRODUCTION

A disturbing trend is the decline in the annual number of living kidney donors in the United States.(1)* Over 130,000 patients with end-stage kidney disease (ESKD) in the United States await kidney transplantation.(1) Kidney transplantation is the optimal therapy for most patients with ESKD, albeit the supply of organs is far below the demand. In 2021, only 13,214 and 5,972 deceased and living donor kidney transplants were achieved, respectively.(2) The U.S. Human and Health services “Advancing American Kidney Health” initiative has aimed to double the number of kidneys available for transplant by 2030.(3) It is well established that living donor kidney transplant provides more graft and patient survival benefits than deceased donor kidney transplant.(4) Yet the proportion of patients who receives kidneys from living donors remains small each year, and inequalities in access to living donation continue. In this article, the authors discuss trends in living kidney donation in the United States and the role of telemedicine services in enhancing access to transplant centers for donor evaluation and follow-up.

CHANGING LANDSCAPE IN LIVING KIDNEY DONATION

Several factors have played a role in the decline in the number of living kidney donors. Racial disparities in the rate of ESKD is a major factor resulting in lower rate of living donor kidney transplantation in certain races. (5–7) ESKD is more common in racial/ethnic minority groups and persons of low socioeconomic status.(8, 9) Potential donors from such low-income families face challenges in handling the cost of travel, lodgings, and lost wages to complete the donor evaluation process. Compared to those with low socioeconomic status, ESKD patients with high socioeconomic status have greater probability of living donor kidney transplantation.(10) Further, there are variations in demographic characteristics and clinical outcomes among donors.(11–16) Uninsured donors and those who reside out-of-state relative to the transplant center have lower odds of medical follow-up, which can predispose them to poor outcomes.(17–19)

THE DECLINE IN LIVING KIDNEY DONATION

The number of donors in the United States have declined over much of the last two decades (Figure 1), based on Organ Procurement and Transplantation Network (OPTN) data as of June 30, 2022. The decline in donor number was initially observed in 2005. A national registry study of 77,427 donors estimated the change in the annual number from 2005 to 2017. (20) The authors used a stratified regression analysis by donor/recipient relationship, race/ethnicity, and donor age. The results show an overall decrease in the number of biologically related donors across race/ethnicity, except for Hispanic donors over the age of 50. On the contrary, the authors observe an overall increase in the number of unrelated donors across race/ethnicity, except for unrelated black donors under the age of 50. The aggregate effect of these trends was a decline in the number of donors in the United States, given the majority of donors were traditionally biologically related. These trends parallel the evolving literature about the increased long-term risk of kidney disease for biologically related, black, and younger donors.(21–24) While the relative risk of ESKD in donors appears to be high (5–11 times) compared with matched nondonors, the 15-year absolute

risk is notably low, less than 1%. Miscommunication leading to skewed risk perceptions needs to be addressed and better clarified. Even so, this evolving literature may not justify the decline that began in 2005. It is plausible that this downward trend among biologically related donors was associated with the tumultuous economic period in the United States (the great recession), especially because ESKD is more common in low-income families. Efforts are needed to help engagement of potential biologically related donors combined with reliable work-up to risk-stratify more accurately the long-term outcomes in these potential donors.

THE INCREASE IN LIVING KIDNEY DONATION

After the decline in the number of donors from 2005 to 2017, the transplant community observed a rise in the number of donors from 2017 to 2019, and in 2019 was the record number (N=6,858) of donors in the United States (Figure 1). A study analyzed a national registry of 35,900 donors to identify the donor attributes underlying the rise in the number of donors in 2017 to 2019 vs. 2014–2016.(25) This study reveals that unrelated and paired white donors were the main drive of the increase in donation. However, it shows significant declines in unrelated black donors and a continuous lack of growth in biologically related donors across all race/ethnicity, except for black and Hispanic donors over the age of 50. These findings highlight the need for programs supporting living kidney donation by unrelated black persons.

THE EFFECT OF THE PANDEMIC ON LIVING KIDNEY DONATION

The coronavirus disease 2019 (COVID-19) pandemic struck living kidney donation in 2020, leading to the lowest annual number (N=5,234) of donors in the United States in the last two decades, a trend that has not recovered well in 2021 (Figure 1). Access to transplant centers was limited due to the pandemic. Transplant programs restricted in-person evaluations for potential donors due to logistics challenges and the limited number of patients and providers per clinic space. These trends call for national strategies to enhance access to living kidney donation beyond the pandemic.

CHALLENGES TO COMPLETE LIVING KIDNEY DONOR EVALUATION AND FOLLOW-UP

Persons who consider kidney donation encounter geographic, financial, and logistical obstacles to engage with transplant centers, especially those being socio-economically disadvantaged.(26–28) A study reports that half of donor candidates had to travel 50 miles to come to the transplant center to start donor evaluation and counseling.(6) Longer distance from a transplant center is linked with higher donor out-of-pocket costs.(29, 30) Donor evaluation is a complex multiphase process, which typically involves transplant nephrologists, surgeons, independent living donor advocates/social workers, and nurse coordinators, and not infrequently requires psychologists or psychiatrists for counseling. This process remains challenging and lengthy.(31, 32) Approximately 50% of the evaluated donor candidates proceed to donation, while a substantial proportion cannot complete the initial in-person visits for donor evaluation due to personal, social, and logistical constraints. (6, 33) Additionally, persons who have donated a kidney receive inadequate follow-up care. (12, 18, 19)

TELEMEDICINE SERVICES TO ENHANCE ACCESS TO LIVING KIDNEY DONOR EVALUATION AND FOLLOW-UP

Telemedicine using a live-video visit enables real-time health care delivery without an in-person clinic visit. Live-video visits permit a potential donor and provider to interact remotely using reliable and consumer-friendly videoconferencing software via a secure internet connection. As such, transplant centers can begin evaluating and counseling potential donors using telemedicine, especially for persons who have hurdles to coming for an in-person visit. Likewise, transplant centers can employ telemedicine to optimize post-donation follow-up care while avoiding the inconvenience of travel and related expenses. (34–36)

TELEMEDICINE PRACTICE ACROSS U.S. TRANSPLANT CENTERS

Heterogeneity in telemedicine practice across U.S. transplant centers exists. In a national survey of multidisciplinary providers at adult living donor kidney transplant centers,(37)** 70% of 128 represented centers plan to continue using telemedicine services for donor evaluation and/or follow-up care beyond the pandemic, while only 28% of centers used telemedicine prior to the pandemic. Utilization of telemedicine modalities varies by provider role. For donor evaluation and counseling, nephrologists, surgeons, and psychologists/psychiatrists used video primarily. Independent living donor advocates/social workers used both video and telephone, while nurse coordinators used video or telephone equally. For the donor follow-up care, both video and telephone were used. The study shows that providers across specialties are favorably disposed to utilize telemedicine for donor evaluation and follow-up beyond the pandemic (Figure 2). However, providers perceive payor rules and reimbursements and out-of-state licensing as key barriers to sustaining and expanding telemedicine practice. Further, this study underlines the persons that can highly benefit from telemedicine services, those who have limited access to a transplant center (e.g., distance), have limited financial/work support, have limited social/caregiving support, or reside out-of-state.

PRE-DONATION TELEMEDICINE SERVICES

Potential donors can begin the evaluation process using telemedicine. The potential donor can be at a local clinical facility or home (originating site), while the provider can be at a clinic or an office (distant site). Transplant providers can educate and counsel potential donors virtually, making an informed decision-making for kidney donation. Potential donors can use a local provider office, pharmacy, or laboratory amenity to record vital signs. Transplant centers can coordinate completing required laboratory tests and imaging locally. Persons who are considered appropriate donors can come in person to the transplant center to complete the physical examination and meet with the transplant team before the donor committee clearance or thereafter including a few days prior to the scheduled donor nephrectomy. The estimated out-of-pocket expenses for a donor is estimated to be \$5,000. (22) Transplant centers can use telemedicine to ease the donor evaluation process and reduce donor out-of-pocket costs, whether a potential donor advanced to donor nephrectomy or not.

POST-DONATION TELEMEDICINE SERVICES

The transplant community recognizes inadequate follow-up care for donors. Many donors lose the OPTN/ United Network for Organ Sharing (UNOS) mandated follow-up despite the requirement that transplant centers complete data collection at 6, 12, and 24 months post-donation.(12, 18, 38) Geographic distance, travel burden, and logistics are challenges to maintain continuity of care for donors.(18, 39) Telemedicine has the potential to enable follow-up with high-quality care.

FACTORS INFLUENCING THE IMPLEMENTATION OF TELEMEDICINE FOR LIVING KIDNEY DONATION

Transplant centers accelerated the adoption of telemedicine services in reaction to the pandemic under the Public Health Emergency (PHE) and improved funding for telemedicine infrastructure by the Coronavirus Aid, Relief, and Economic Security (CARES) Act.(40–42). However, most centers report difficulties in sustaining and expanding telemedicine services beyond the pandemic.(43) While both traditional in-person visits and telemedicine visits have their strengths and weakness, support from involving stakeholders and execution of proposed strategies should sustainably allow the implementation of telemedicine to enhance access to living kidney donation and improve care coordination for donors (Table 1). The implementation of telemedicine services for living kidney donation is influenced by policy/regulatory, donor, provider, and institutional factors.

Payor and state licensure restrictions are the major barriers to telemedicine practice.(44) Telemedicine policy/regulatory restrictions have been relaxed temporarily due to the PHE. (45–48) Historically, Medicare restricted telemedicine services. In 2019, Medicare made exceptions to geographic and originating site constraints for specific telemedicine services, including home dialysis patients.(49, 50) On March 6, 2020, the Centers for Medicare and Medicaid Services (CMS) expanded access to telemedicine services under the CARES Act and Section 1135 waiver authority.(40, 46, 51) Medicare now reimburses telemedicine video visits across states as if they were in person, regardless of the beneficiary's physical location and provider new or established relationship.(44) Similarly, different private payors have embraced the same policy to the CMS.(48) However, the CMS relaxed policy/regulations expire at the end of the PHE. Excitingly, on July 27, 2022, the U.S. House of Representatives passed a bill, Advancing Telehealth Beyond COVID–19 Act of 2021 that would extend telemedicine waivers until December 31, 2024.(52) Yet, state's licensing requirements override the CMS waivers to expand telemedicine across states.(48) Potential donors may come from various states, and kidney-paired donation is growing to allow incompatible donor/recipient pairs across States.(25, 53, 54) Most states waivers for telemedicine services are now expired or restricted which hinder efforts to grow living donor kidney transplantation, a lifesaving procedure.

Most people have access to smartphones and high-speed internet, which is essential for using video visits.(55) It is critical to support persons with low income or in rural areas with telemedicine services, as this can improve their access to transplant centers.(56) Education kits are needed to help a person navigate telemedicine services, and immediate support for

troubleshooting must be available. Patient confidentiality should be protected in accordance to HIPPA rules. Language services must be provided to non-English speakers.

While many providers across specialties are willing to use telemedicine beyond the pandemic,(37)** they need education and training about best practices for using telemedicine and performing a limited physical examination virtually. Providers also need to be empowered with staff and technology support and private space to provide high standards of care.(43, 57, 58) Healthcare leadership support to providers is vital in expanding telemedicine practice. It is worth noting that a lack of incentives for providers using telemedicine can negatively impact the growth of this practice. While transplant centers can miss a facility fee when utilizing video visits, this business disincentive does not apply to donor evaluation because payors reimburse pretransplant evaluations for the donor and recipient under organ acquisition costs.(59)

Institutional support of telemedicine infrastructure is important. Healthcare systems need to invest in appropriate technology and equipment and recruit qualified staff to advance the use of telemedicine. Financial contracts between institutions may be required to help complete a donor physical examination and additional consults locally, especially for those who come from out of state. Institutions must establish legal advisory and administrative teams to inform providers with guidance about updated policies and regulations for telemedicine practice.

FUTURE DIRECTIONS

It is essential to conduct research studies to examine the effect of telemedicine services on donor outcomes, including times to complete the donor evaluation process, rates of donor nephrectomy, and completion of mandatory donor follow-up care. Further, there is a need for qualitative research to understand donor perception of telemedicine using live-video visits. Other areas of interest include innovative studies to overcome the limitation of physical examination. Evidence-based guideline will help establish the standard and best practice in telemedicine for donor evaluation and follow-up.

CONCLUSION

Trends in living kidney donation in the United States raise awareness about the lack of growth among biologically related donors across race/ethnicity, and unrelated black donors. Remarkably, unrelated donors, except for blacks, have become the majority of donors in this changing landscape of living kidney donation. These trends, with an overall decline in the number of donors, call for interventions to help engage and support potential biologically related donors and unrelated black donors. Geographic and socioeconomic barriers contribute to inequalities in access to living kidney donation. Telemedicine services can enhance access to transplant centers and facilitate donor evaluation and follow-up care. However, expanding telemedicine practice depends largely on payor policy, state regulations, and telemedicine infrastructure. There is a need for federal and state permanent legislation to support telemedicine services for donors across state lines, in alignment with the Advancing American Kidney Health initiative to improve access to kidney transplantation.(44, 60). In addition, studies to advance the utilization of telemedicine

services and assess their impact on donor outcomes are needed and should receive priority funding from research institutes.

Acknowledgements

The authors would like to thank the telemedicine workgroup, American Society of Transplantation's Living Donor Community of Practice for its efforts in advancing telemedicine services for living kidney donors.

This work was supported in part by Health Resources and Services Administration contract HHS250-2019-00001C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Financial support and sponsorship

This work was supported by the National Institute of Diabetes and Digestive and Kidney Diseases: K23DK129820 (awarded to Dr Al Ammary), and the National Institute on Aging: K08AG065520 (Awarded to Dr. Muzaale).

Primary Funding Source:

National Institute of Diabetes and Digestive and Kidney Diseases and National Institute on aging.

ABBREVIATIONS:

COVID-19	The Coronavirus 2019
CARES	Coronavirus Aid, Relief, and Economic Security
ESKD	End-Stage Kidney Disease
ILDAs	independent living donor advocates
OPTN	Organ Procurement and Transplantation Network
PHE	Public Health Emergency
UNOS	United Network for Organ Sharing
U.S.	United States

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* of special interest

** of outstanding interest

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KEY POINTS

- Biologically related living kidney donors have experienced a lack of growth since 2005.
- Unrelated donors have emerged as the majority of living kidney donors in recent years, except for unrelated black donors.
- Telemedicine services can help reduce inequalities in access to living kidney donation and facilitate engagement of potential donors to complete their evaluation and follow-up.
- Expanding telemedicine practice will need permanent federal and state legislation to support telemedicine services across state lines and to reimburse video visits at the same rate as if these visits were in person.

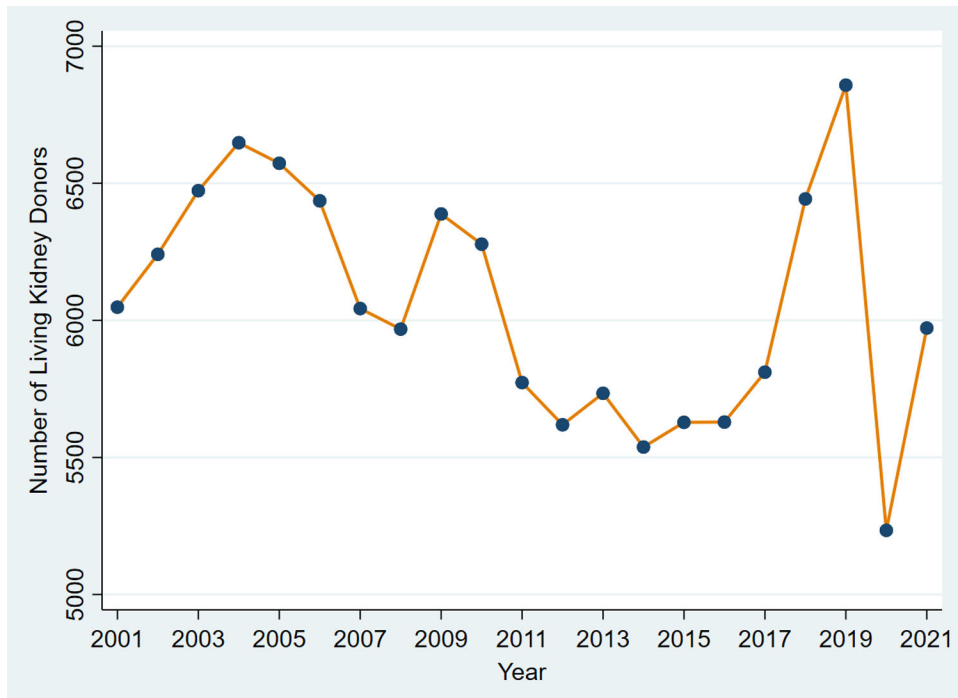


Figure 1.
Annual number of living kidney donors in the United States from 2001 to 2021
Based on Organ Procurement and Transplantation Network (OPTN) data as of June 30,
2022.

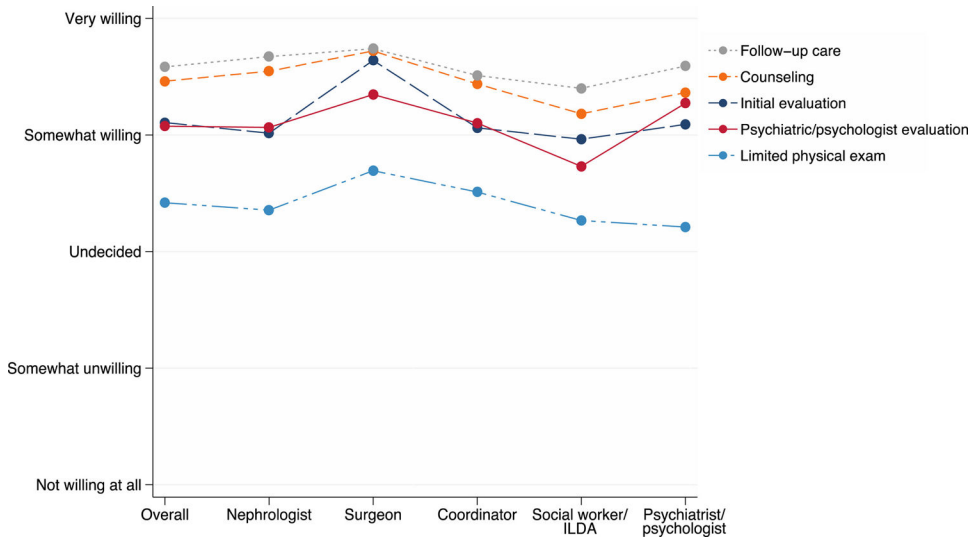


Figure 2. Willingness of multidisciplinary providers to use telemedicine services for living kidney donation beyond the COVID-19 pandemic. Overall, respondents were very willing to use telemedicine for counseling potential donors (mean response, on a 5- point Likert scale, [standard deviation]: 4.5 [0.8]) and post-donation follow-up care (mean response: 4.6 [0.7]). Respondents were somewhat willing to use telemedicine for the initial evaluation (mean response: 4.2 [1.2]) or psychiatric or psychological evaluation (mean response: 4.1 [1.1]). However, respondents were undecided whether they would use telemedicine to conduct a limited physical exam (mean response: 3.4 [1.3]). ILDA, independent living donor advocate. Adapted from Al Ammary et al.(37)

Table 1:

Comparing features of care delivered through in-person versus telemedicine visits and proposed strategies to improve care coordination for living kidney donors using telemedicine

Stakeholders	In-person visit	Telemedicine visit	Strategies to implement and sustain telemedicine services for living kidney donation
Government / Insurers			
<i>Rules</i>	Hospital office space	Restrictions to donor geographic location	Permanent rules to expand telemedicine services coverage without geographic restrictions
<i>Reimbursements</i>	Covered under the organ acquisition cost	Covered under the organ acquisition cost	
<i>State Regulation</i>	State medical license	State medical license	
<i>Out-of-state restrictions</i>	Loss of out-of-state donor engagement	Engagement of out-of-state donors and requirement of out-of-state medical licenses	Permanent policies to allow out-of-state licensed transplant providers to provide telemedicine services across states
Persons considering Living kidney donation			
<i>Time to evaluation</i>	Time spent traveling, especially those who come from a far distance	Logistics to set up virtual connection and technical issues	Staff support to ensure visit connection and troubleshoot technical issues
<i>Cost</i>	Cost for transportation and accommodation and lost wages	Access to electronic devices and cost of internet	Logistics support to ensure access to electronic devices and high-speed internet, especially for those with low income or in rural areas
<i>Care partners</i>	More difficult to join in-person visits	Easier to join virtual visits	Facilitate engagement of family/caregivers to support donors
<i>Language</i>	Availability of on-site interpreters	Challenging for providing 3-way communication between a patient, provider, and interpreter	Dedicate language services for non-English speakers using telemedicine services
Transplant providers			
<i>Staff support</i>	Built-in within a clinic structure	Logistics for setting up virtual visits and technical issues	Multidisciplinary providers support to deliver high care quality
<i>Education</i>	Easier to make in-person communication	Learning a non-verbal language to guide virtual communication	Establish effective communication training for telemedicine services
<i>Physical exam</i>	In-person complete exam	Virtual limited exam	Provider training to conduct limited virtual exams and engage local primary care providers IT support to integrate donor data sources directly into electronic medical records
Institutes			
<i>Infrastructure</i>	Established within a center structure	Technology and equipment with staff support	Administrative and technology support for telemedicine services
<i>Space</i>	Clinic rooms to accommodate visits	More flexible for scheduling	Accommodate flexible schedule for telemedicine visits
<i>Research support</i>	Logistics challenges to incorporate clinical research around in-person visits	Logistic challenges to incorporate clinical research around virtual visits	Establish a dedicated telemedicine team to support research for telemedicine services